MEETING MINUTES STATE CONSUMER FAMILY ADVISORY COMMITTEE MAY 5, 2004

<u>Present</u>: Jere Annis, Carl Britton-Watkins, Derl Bruce, Pete Clary, Zac Commander, Sandy Dupuy, Ron Huber, Kathleen Herr, Ben Jones, Ed Masters, Doug Michaels, Ellen Perry, Barbara Richards, Katie Sawyer, Betty Stanberry, Alex Vasquez, and Paula Wagner.

Absent: Amelia Thorpe

<u>DHHS Staff Present</u>: Lori Bailey, Donnie Charleston, Felissa Ferrell, Cathy Kocian, Michael

Moseley, Carmen Hooker Odom, Chris Phillips, Ann Remington, Wes Rider

Facilitator: Beth Melcher

I. Welcome and Introductions

Ann Remington introduced DHHS staff.

Consumer Empowerment Team members were introduced: Lori Bailey (Asheville office), Donnie Charleston (Raleigh office), Felissa Ferrell (Greensboro office), Cathy Kocian (Charlotte office) and Wes Rider (Onslow/Eastern Region). Ann advised the SCFAC to feel free to contact any of her staff with questions and concerns.

Chris Phillips, Chief of Advocacy and Customer Services, thanked everyone for their time and involvement. The principle of consumer and family involvement is very progressive in North Carolina and focuses on consumer/family-driven planning, implementation, and policy making. Chris told the group of his becoming convinced of the sincerity of the State's commitment to this principle during his job interview. At that time, he said, Secretary Hooker-Odom shared with him an experience of being able to problem-solve in a service area due to having received direct input from advocates and consumers. He told the SCFAC that they will have a huge range of issues on which to focus and that it will be important to prioritize in order to be effective.

Ann Remington, Team Leader of Consumer Empowerment Team, explained how she began her career in advocacy. Her experiences with family members dealing with the courts, DSS, psychiatric hospitals, the criminal justice system and IEP at schools led her to learn about the rights of children. It became very clear to her that there was a need for consumer and family involvement. This is a movement and we don't want it to go away. It is imperative that we have the tools to use in order to access the system. She also cautioned about the decreasing need for vigilante behavior, now that we are at the table. Ann stressed the importance of taking personal issues and passions and using them to strategize in order to make system changes that happen over time. She said that everyone present today will be able to use their local CFAC experience and build upon that experience.

Carmen Hooker Odom, Secretary of DHHS, stated that she was glad the SCFAC was finally launched and that it would have a big impact on reform. She elaborated on Chris' story about the consumers and family members who approached her and described how they wanted to talk about the system. This group of people spoke of needed changes in a completely different way from self-proclaimed advocate leaders. Carmen mentioned the person-centered process and how consumer and family perspective is at the center of the reform. She stressed the fact that SCFAC members report directly to her and that she doesn't want anything filtered. She also stressed to the members present that they have direct access to her. She asked that SCFAC

members identify affiliation to SCFAC when corresponding with her via email. Carmen went on to say that "creative tension is absolutely necessary to move the reform forward and that she is very passionate about mental health and basic civil rights and social justice." She noted that there has been too much reliance on institutional care and that the system is shifting funds from the institutions back into the local communities. People with disabilities will have an opportunity to live in their own communities. She also stated "it is a fundamental denial of basic human rights" to be inappropriately institutionalized. In conclusion, it was also mentioned that consumers want choice and that the underpinning of the entire reform is the SCFAC and local CFAC groups. She said to remember that her "door is always open and SCFAC members need to feel free to contact me at any time."

Michael Moseley, Director of DMH/DD/SAS, gave a brief overview of the SCFAC responsibilities and expectations. He explained that quality is defined by customer satisfaction and that we need to ask if our customers are satisfied. Mike told a story about a man who many members of society might refer to as a "bum" that he encountered while wiping off his car in front of a mall while waiting for his wife to come out. At first he thought the man was going to ask him for money, but the man never did ask him even after telling Mike that he sure had a pretty car. It dawned on him that maybe he could ask the man if he needed any help and the man replied, 'Don't we all?" These three words shook him as he was feeling above the "bum in the street" and "no matter how much you have accomplished, you need help too. No matter how little you have, no matter how loaded you are with problems, even without money or a place to sleep, you can give help." Mike asked the SCFAC to "please question our assumptions and challenge our plans as they must be person-centered and communityfocused." Mike described his life in detail as he explained his own encounters with public housing, discrimination, being called names he would not repeat, being used and abused, as well as having to work harder and excel more than anyone else. He then proceeded to speak about Dean Smith, the former basketball coach at UNC, who wrote a book identifying three goals: play hard – do your best, play smart – stay focused on the task at hand, and play together – recognize that teamwork is the ultimate answer to life's successful journeys. Mike stated that it is important to keep in mind the following things:

- Don't allow what you do to affect who you are.
- · Do your job, but remember your mission.
- Don't let what we do get inside of you. You should influence us, not let us influence you.
- Increase your ability to work with different people and listen to their viewpoints as well
- Remember that where you are does not determine where you are going. This will keep you from becoming frustrated. Keep your eye on the prize. Said another way, don't stress yourselves out over what the MH/DD/SAS system currently provides, but continue to work towards what the system is expected to provide in the future.
- Get the best results with minimal confusion. Be effective without just making noise.
- · Work with everybody. Use all of your gifts.

Mike gave his word that the SCFAC will have his staff's full cooperation and that the division will be timely in responses. He encouraged everyone to tell him on what level of and how they would like to interact with him. In closing, it was strongly suggested that the SCFAC members stand up for what they believe in, keep a smile on their face, show their true strength, do what

is in their hearts and hold their head high. These qualities, along with "courage, strength, determination, compassion, loyalty, selflessness and confidence mean an effective member of the SCFAC."

II. The S-CFAC members introduced themselves:

- *Carl Britton-Watkins*: Rockingham County resident, Director of Durham County Council on Alcoholism and member of the Durham CFAC.
- *Barbara Richards*: Son with OCD, child parent advocate in the school system, resident of Catawba County and daughter of an alcoholic.
- *Paula Wagner*: Secretary of Catawba CFAC, MH and physical disability, part-time worker at Catawba Mental Health and involved with a clubhouse.
- *Jere Annis*: Smokey Mountain CFAC, member of the ARC for many years and served on the ARC back in the 1970's when the ARC sued the state for compensatory damages.
- Zac Commander: Co-Chair of the Albemarle CFAC, Vice Chair of the Mental Health Association and active on the Human Rights Committee.
- Katie Sawyer: Tidelands area, involved with Mental Health for over seven years.
- *Ron Huber*: Involved with Mental Health since he was a teenager. 35 year-old daughter is DD. He is Director of Special Ministries in Sanford for hearing impaired and persons with disabilities. Retired since 1999, he is an active advocate in the reform.
- *Ellen Perry*: has Cerebral Palsy, member of NC DD Council, CFAC Co-Chair for Orange County, and Girl Scout leader for a "normal" troop.
- *Derl Bruce*: CFAC member of Crossroads, consumer since youth.
- *Sandy Dupuy*: Chair of Mecklenburg CFAC, 3 adopted children (1-SA, 1-DD, and 1-MH suffers from Depression), Family history of SA and MI.
- Alex Vasquez: Co-Chair of Cumberland County CFAC.
- Ben Jones: 18 years old, has appeared on a panel in Portland, Oregon.
- *Ed Masters*: Advocate for a family member with mental illness. Involved with local NAMI, CFAC, and the Human Rights Committee at Cherry Hospital.
- *Pete Clary*: Resides in Winston Salem, on the LME board, a public defender for Forsythe County and has represented MI. He has an 11 year-old daughter with RETT disability and has been active on many boards including NC TASH.
- *Doug Michaels*: In recovery from addiction disease, ACOA, has 5 adopted children 3 of whom have drug and alcohol problems. Founder of VOICES for Recovery in Asheville and has a brother with a developmental disability.
- *Kathleen Herr*: Concerned about systems issues, has 4 children (1-epilepsy, 1-DD, and 1-severe MI).
- Betty Stanberry: Sr. Vice President ARC Board and has a son with a disability.

III. Division organization- Power Point presentation. Complete presentation distributed in SCFAC binders to each member.

- Participant-driven system
- Diagram detailing the SCFAC and its proper place at the center of reform
- Executive Leadership Team (ELT) consisting of Michael Moseley, Leza Wainwright, and the 5 Section Chiefs: Chris Phillips, Don Willis, Phillip Hoffman, Flo Stein, and Stan Slawinski.
 - The SCFAC reports to the DHHS Secretary.

- The SCFAC will also meet with the Secretary at least annually to provide a summary.
- The S-CFAC membership will have 21 members with equal representation of all four disability groups.
 - Three vacant adolescent positions need to be filled: SA, DD, and MI.
 - SCFAC terms of office.
 - 6 members appointed for an initial one-year term.
 - 7 members appointed for initial two-year term.
 - 8 members appointed for initial three-year term.
 - All subsequent appointments will be for three-year terms.
 - Members appointed for an initial one or two-year term may be re-appointed for a full three-year term.
 - Individuals should not be appointed to more than two consecutive terms.
- Times, dates and locations of SCFAC meetings:
 - Meetings will be held at least monthly and with ELT or other staff as needed.
 - Group will decide the number of meetings, dates and locations.
 - SCFAC Supports
 - Felissa Ferrell will assist from the Division as staff support.
 - Cathy Kocian will assist with minutes.
 - SCFAC members approved the use of a tape recorder for recording meetings.
 - SCFAC members were asked to contact the appropriate person if they are unable to attend a meeting and may also contact any staff member on the Consumer Empowerment Team.
- The SCFAC work plan should be developed by the SCFAC with direction from the DHHS Secretary and the Division Director.
- SCFAC purpose and work plan:
 - Mike Moseley stated that the volume of information and the opportunity to address issues will be overwhelming so, as a group, it is important to prioritize.
 - Comments evolved around performance indicators and SCFAC education and training needs.
 - Concerns were expressed concerning the mission of SCFAC. It was noted that once the SCFAC decides on a project, they will be the eyes and ears of the state, inform the state what is right and wrong, advise the Secretary and Director and provide insight on how reform is working.
 - Additional comments about the speed of the reform were addressed and Mike
 Moseley reminded everyone that it's important that the momentum isn't lost. In
 addition, we have to keep the legislators on board for their support.
 - Mike Moseley added that he has already stated, "If we are not ready to do certain things then we will have to slow it down and make it right."
 - It is also important to remember that we represent the people across the state.
 - One thing SCFAC can not do is speak for the Division. The SCFAC is an advisory group, not a policy group.
 - The SCFAC will help the division improve the quality of service across the state.
- The organizational chart of Division was reviewed.
- The mission statement of the Division was read.
- Division Sections:
 - Advocacy and Customer Services
 - Consumer Empowerment Team

- Customer Services and Community Rights
- State Facility Advocates
- Administrative Support
 - Communications and Training
 - Division Affairs- Collaborative efforts of DHHS
 - Planning The SCFAC will be "tracking" and offering input into division planning.
- Resource and Regulatory Management
 - Accountability
 - Budget and Finance
 - Contract Management and Development
 - Information Systems
 - Regulatory
- State Operated Services
 - Regional Psychiatric Hospitals
 - Developmental Disability Centers
 - Alcohol and Drug Addiction Treatment Centers (ADATC)
 - Child Treatment Programs
- Community Policy Management
 - Best Practice and Community Innovation
 - Justice Systems Innovation
 - Local Management Entity Systems Performance
 - Early Intervention and Prevention
 - Quality Management
 - Employee Assistance Program

IV. *Beth Melcher, SCFAC facilitator contracted by the Division*, will assist the SCFAC in the short term prior to it's deciding on matters of facilitation and leadership.

Beth's background: Prior to contracting with the Division, Beth worked in a leadership position with NAMI. She has been working with NC Science to Service Project where she manages a grant on Evidenced-Based Best Practices. In addition, she has a long family history of mental illness and substance abuse. Beth's role with the SCFAC is to assist the group in the following ways:

- Will facilitate next 3-6 sessions,
- Will assist SCFAC in forming effective communication within the group and
- Will act as a moderator (not to prescribe plans).

V. Key Points in Becoming an effective committee

- Understand your role and purpose do not engage in investigative or individual advocacy.
- Develop procedures by-laws and meeting procedures.
- Respect each other and commit to a common purpose be willing to communicate and compromise.
- Focus prioritize issues and establish a work plan.

VI. How to Set Priorities

Establish a set of guiding principles to assist with prioritizing. Pick 3 issues to work on and examine how you made your choice.

- Setting priorities is the beginning of the fulfillment of the SCFAC mission as we develop a work plan.
- Three areas of focus the SCFAC believes are priorities:
 - o Consumer services:
 - Ouality.
 - Gaps and needs,
 - Effectiveness of services.
 - o Support CFAC growth and development at state and local level.
 - o Support individual (consumer) participation at state and local level.

VII. Organization of SCFAC

- The group decided that they need the opportunity to get to know each other through some informal dialogue and also to discuss the development of "rules or code of conduct."
- Bylaws- can start filling in sections as we move along.
- Officers
 - Chair/Co-Chair (however some prefer a different title).
 - Would be the spokesperson for the group,
 - Would act as the primary liaison with support staff and the Division,
 - Would develop the agendas,
 - This position would involve a real time commitment.
- It was decided not to create and use an Executive Committee.
- In order to pass a motion, a vote equaling half the total membership plus one would be required.
- Proxy vote was determined to be acceptable.
- Support needed for the SCFAC:
 - Secretarial assistance (use of tape recorder will also be permitted for note taking)
 - Consumer Empowerment Team Liaison
 - Clear method of communication
 - Training
 - Spread meetings across the state so everyone has equal responsibility with driving It was strongly suggested that the group meet once a year in the mountains and once a year at the ocean. Video conferencing could also be done at different locations and the Consumer Empowerment Team person will be the point person at each location. The group could then meet quarterly in person. This would assist the members with consideration for driving time.
 - Meals and mileage will be paid. The driver of SCFAC member will also receive mileage and meals.
 - It is the goal to have hotels pre-paid by the Division in the future.
 - Stipend will be \$15.00 per day.

VIII. Next Meeting

- Thursday, June 10, 2004, 9:30-3:30p.m. in Raleigh. Location will be announced.
- Agenda items:
 - 3 main priorities from section VI of the minutes,
 - Review of draft by-laws,
 - Training needs and
 - Sub-committee needs.